Palliative and Supportive Care

cambridge.org/pax

Conducting a narrative medicine workshop in ambulatory palliative care: A feasibility and exploratory study

Gregory Heinonen, B.A.[1], Maura Spiegel, PH.D.[2] and Craig D. Blinderman, M.D., M.A., F.A.A.H.P.M.[3]

[1]Vagelos College of Physicians & Surgeons, Columbia University, New York, NY, USA; [2]CUIMC Division of Narrative Medicine, Columbia University in the City of New York, New York, NY, USA and [3]Adult Palliative Care Service, Columbia University Irving Medical Center, New York, NY, USA

Original Article

Cite this article: Heinonen G, Spiegel M, Blinderman CD (2023). Conducting a narrative medicine workshop in ambulatory palliative care: A feasibility and exploratory study. *Palliative and Supportive Care*. https://doi.org/10.1017/S1478951523001499

Received: 10 August 2023
Revised: 08 September 2023
Accepted: 18 September 2023

Keywords:
Ambulatory; Narrative Medicine; Palliative Care

Corresponding author: Craig D. Blinderman; Email: cdb21@cumc.columbia.edu

Abstract

Objectives. This pilot study aimed to assess the feasibility and impact of a narrative medicine group for patients receiving palliative care.

Methods. This pilot study aimed to assess the feasibility of a six-session, physician-led narrative medicine group for patients receiving palliative care. Ten patients were recruited by their outpatient providers. Symptom severity and patient dignity scores were collected pre-intervention, at the mid-point, and post-intervention using the Patient Dignity Inventory (PDI) and Edmonton Symptom Assessment Survey (ESAS). Qualitative reports of pain, expectations, and anticipated challenges were collected before the intervention. Participant interviews were conducted after the intervention to assess overall experience in the group, challenges experienced, recommendations for future endeavors, and general feedback.

Results. No significant changes in PDI or ESAS scores were observed at baseline, 3 weeks, and 6 weeks. Participants reported overall satisfaction, with 8 of 9 participants stating they "strongly agree" they would participate in the group again and recommend the group to others. Qualitative responses indicated benefits in the realms of relating to other patients, subjective reduction in pain, and relieving feelings of isolation.

Significance of results. A narrative medicine group for ambulatory patients receiving palliative care appeared to be both beneficial and feasible when delivered through a virtual format. A randomized trial with a larger sample is needed to fully assess the impacts of engaging in narrative work on symptom burden, survival, and quality of life.

Introduction

Narrative medicine is "an international discipline at the intersection of the humanities, the arts, clinical practice, and health care justice with conceptual foundations in narratology, phenomenology, and liberatory social theory" (Division of Narrative Medicine, Columbia University 2020). The initial aim of the field was to improve clinicians' capacity to be moved by the stories of their patients – improving attention, representation, and affiliation. These benefits of narrative medicine could also be of value for seriously ill patients in outpatient palliative care clinics, who struggle with engagement, isolation, and questions of meaning.

Narrative medicine interventions have been implemented in multiple clinical and training settings for health care providers and students, and more recently for patients as well (Charon 2001; Morris 2008). A 2016 systematic review identified 10 studies where narrative medicine was used as a clinical tool. Though methodology, study population, intervention structure, and outcomes vary, results suggest that narrative medicine may be a useful tool for decreasing pain and increasing well-being in patients with chronic medical conditions such as cancer, HIV, and asthma (Petrie et al. 2004; Rosenberg et al. 2002; Smyth 1998; Stanton et al. 2002). The benefit of writing and emotional disclosure has also been seen in patients with life limiting illness, with favorable outcomes seen in the use of self-compassion instruction paired with writing about stressful experiences of hospice patients (Imrie and Troop 2012).

Notably, much of the existing literature explores emotional disclosure through writing that is not shared externally. However, disclosure through verbal communication as a therapeutic method may offer additional benefits. In a study of palliative care patients with moderate to severe depression, participation in a narrative-focused interview with a trained research staff was associated with decreased depressive symptoms and prolonged survival (Lloyd-Williams et al. 2018). Similarly, in a trial of hospice patients randomized to a one-on-one narrative interview in which patients were encouraged to "tell their story" and reflect on their sense of meaning regarding their suffering, those who participated demonstrated decreases in anxiety

and depression severity (Lloyd-Williams et al. 2013). Previous work has also found that patients appreciated seeking support from fellow palliative care patients at a day program, given the shared understanding and experience that their families may not be able to understand (Low et al. 2005). The relationships formed during group therapy sessions for seriously ill patients are highly valued by participants (Taylor-Ford 2014). Moreover, there appears to be significant interest in opportunities for reflection and expressive writing in this population (Bruera et al. 2008).

Given the potential of narrative interventions in a group patient setting, we sought to evaluate the feasibility and impact of a structured, 6-week narrative medicine intervention in a diverse group of patients receiving specialist-level palliative care practice in an ambulatory clinic in a single, academic medical center in New York City.

Methods

This was a single group pre-post design. Participants were recruited directly by their outpatient palliative care physicians at Columbia University Irving Medical Center in New York City between June and July 2022. Target enrollment was set at 10 participants to facilitate optimal group dynamics and cohesion. Patients were deemed eligible if they were over 18 years of age, were able to read and write in English, had regular access to a computer and Wi-Fi, and were currently receiving care from a palliative care provider. Formal ethics approval was obtained by the Institutional Review Board at Columbia University Irving Medical Center (IRB-AAAU0674). All participants provided informed consent. Surveys were administered by a research assistant not affiliated with the patients' care team. Participants' standard of care was not altered during the study. All data were collected over the phone by research staff.

Self-reported demographic information was collected for all participants including gender, race and ethnicity, and highest level of education completed. Participants were asked to report the primary diagnosis for which they are seeing a palliative care provider. Qualitative data were collected at two points during the study period through standardized interviews that were conducted and transcribed by a member of the research team. During the pre-intervention interview, participants were asked about previous experiences with patient groups, hopes and concerns for participation, and descriptors, qualities, and types of pain (i.e. physical, spiritual, existential). Post-intervention interviews were conducted within one week of the last session and inquired about challenges faced, suggestions for future groups, insights gained regarding their pain, and overall experience. Responses were analyzed using thematic content analysis by one member of the research team. All participants completed two validated assessments at three time-points: before the intervention began (Week 0), at the mid-point of the intervention (Week 3), at the end of the intervention (Week 6). The Edmonton Symptom Assessment Survey (ESAS) measures symptom experience in 10 areas ranging from pain to well-being and asks respondents to score their severity from 0 (least severe) to 10 (most severe) (Bruera et al. 1991). The Patient Dignity Inventory (PDI) assesses the severity of dignity-related distress in patients in various aspects of one's illness experience (i.e. feeling like a burden to others) and ability to care for one's self (i.e. ability to attend to bodily functions independently) (Chochinov et al. 2008). Respondents choose between five Likert scale responses ranging from "Not a problem" (1) to "Overwhelming problem" (5). ESAS and PDI scores were analyzed using Friedman's tests using SPSS. The intervention consisted of six, one-and-a-half hour long narrative medicine sessions.

Table 1. Session themes

	Theme	Writing and discussion prompt	Works used
Week 1	Impact of illness & what is needed for support	*Write about what's broken*	"The Nurse" Jose Perez and "Broken" Frida Kahlo
Week 2	Finding our purpose	*Write about what days are for*	"Days" Phillip Larkin
Week 3	The difficulty of communicating	*Write about "the stillness"*	"The Island of the Sirens" Rilke
Week 4	Being with change	*Write about a time you stayed*	"Between Going and Staying" Octavio Paz
Week 5	Rewriting the illness experience	*How would you write your medical note? If I could add anything to my chart, I would add…*	"Transcription/Medical Record #32-52-52-001 (645 pages)" by Rachel Perry Welty
Week 6	Dependency & Interconnectedness	*Write about what you depend on (or what everything depends on)*	"The Red Wheelbarrow" William Carlos Williams

Narrative medicine sessions were held virtually using video conferencing software (Zoom). The six sessions were designed *a priori* with input from faculty from the Program in Narrative Medicine at Columbia University. The themes addressed and works of art used can be found in Table 1. We adopted the narrative medicine methodology of close reading of a text or visual work of art, led by the group facilitator, followed by 5 min of writing to a short prompt created for each session. Participants were then invited to read what they had written and the group members were encouraged to comment and share what they experienced in the process. Sessions were facilitated by a palliative care physician with additional, graduate level training in narrative medicine. An additional research staff member was available before and during each session to provide technical support.

Results

Eleven patients were recruited to participate in this study. Demographic information can be seen in Table 2. The cohort had a mean age of 52 years old. All participants had at least a high school education. One patient completed the consent process but withdrew prior to the intervention for health reasons. Participants attended, on average, 5 of the 6 sessions (80%). The most common reason for absence was health concerns and symptom burden.

No significant changes were observed in the ESAS or PDI scores throughout the intervention. Average Edmonton Symptom Assessment Scale scores throughout the study are shown in Figure 1. PDI scores are shown in Figure 2.

Nine out of ten patients indicated they had previously participated in support groups though the type of group and experience differed among respondents. Hopes for the group were wide ranging but frequently included a desire to learn and gain new skills ("*I'm excited about the idea of narrative medicine and how it can*

https://doi.org/10.1017/S1478951523001499 Published online by Cambridge University Press

Table 2. Participant demographic information

Participant ID	Age	Gender	Race	Ethnicity	Primary diagnosis[a]	Highest level of education completed
1	72	Male	White	Not Hispanic	Not assessed	Bachelor's degree
2	50	Male	White	Not Hispanic	Systemic AL amyloidosis	Bachelor's degree
3	79	Female	White	Not Hispanic	Metastatic breast cancer	Bachelor's degree
4	70	Female	Black	Not Hispanic	Endometrial cancer	Doctorate degree
5	61	Male	White	Not Hispanic	Not assessed	Bachelor's degree
6	39	Male	Black	Hispanic	Sickle cell disease	Master's degree
7	74	Female	White	Not Hispanic	Acute myeloid leukemia	Master's degree
8	34	Male	White	Not Hispanic	Smoldering systemic mastocytosis	High school diploma
9	29	Male	White	Hispanic	Systemic scleroderma	High school diploma
10	35	Female	White	Hispanic	Cancer	High school diploma
11	31	Female	White	Not Hispanic	Metastatic breast cancer	Master's degree

[a]As reported by participants.

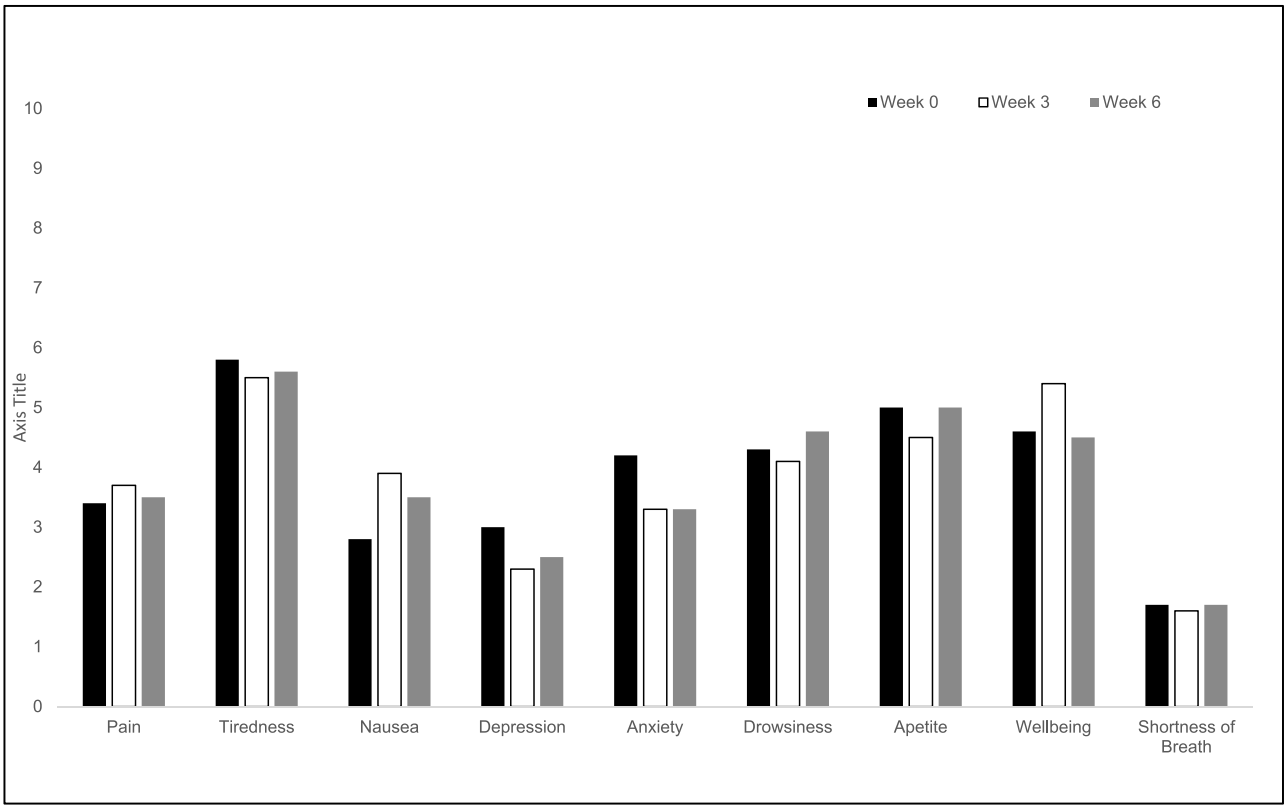

Figure 1. ESAS scores.

help me improve my life") (45%), hearing from other's experiences (i.e. *"hearing what other people's experiences are and if there is anything I can incorporate into my routine"*) (37%), or had no specifics hopes (18%). Reported anticipated challenges included sharing aspects of one's personal life in a group setting (*"If something personal comes up that you haven't thought about myself"*), the use of technology, scheduling or time concerns, comparing one's self to others ("*There will be people in the group who feel better and I'll be jealous or there will be people who feel worse and I'll feel bad"),* and fearing others' stories may bring up emotions in themselves ("*Hearing stories about people who are struggling with coping with terminal illness"*). Likert-scale responses to questions included on the post-participation survey can be seen in Figure 3.

Qualitative assessment

Participation was challenging

One theme that emerged in interviews was that participating in the group was challenging. Three participants noted that it was

https://doi.org/10.1017/S1478951523001499 Published online by Cambridge University Press

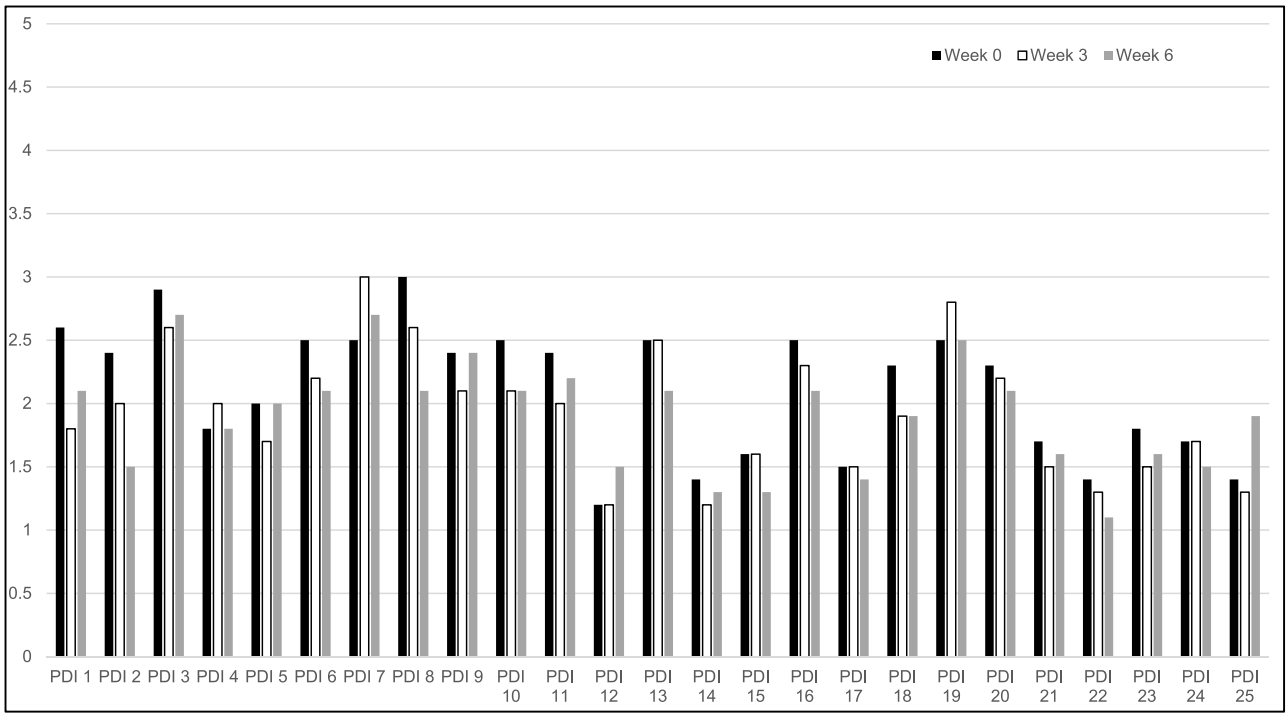

Figure 2. PDI scores.

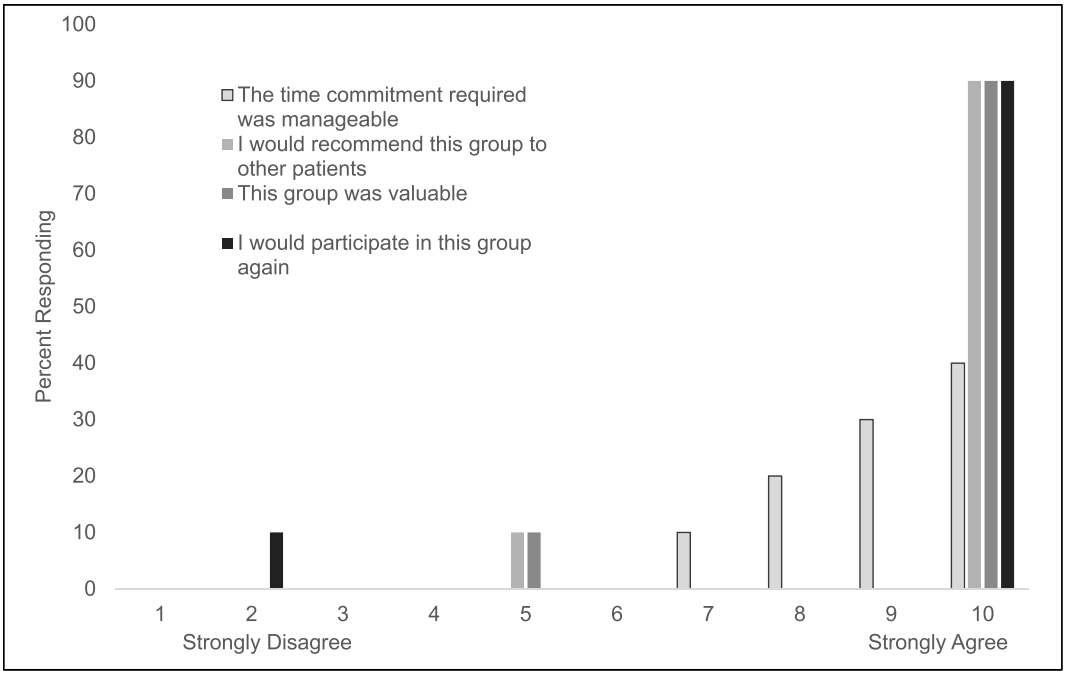

Figure 3. Overall experiences.

challenging to hear about others' experiences. For example, one respondent noted:

> *Admitting to myself how I'm going through a horrible illness but I have such advantages and resources available to me that other people just don't have*

Another stated:

> *One of the things I'm not real fond of in groups is that I'll go and there are people much worse than me and I'll get upset because that could be me. Or I'll go and there are people that are much better than me and I'll get upset because I wish I could be.*

Multiple participants reported they found it challenging to come up with something to say and, at times, felt like there was a pressure to participate.

https://doi.org/10.1017/S1478951523001499 Published online by Cambridge University Press

Articulating anything is difficult and then actually putting out something that I composed or how I feel about something someone else composed is usually a level of vulnerability I don't share, let alone in a group

I felt pressure sometimes to say anything. To have some kind of concrete point. I felt like a little pressure – like school to me, in the beginning

Similarly, participants commonly expressed concerns with their ability to be vulnerable and share their stories with others.

Finally, other issues such as technical challenges with Zoom, trouble staying focused, and managing time constraints were reported by one participant each.

Appreciation and subjective benefit

Another theme that was identified was broad appreciation for the group. Participants noted feeling supported and learning from their fellow participants in various domains. For example, one participant reported tangible informational gains for navigating the healthcare system:

Hearing how people managed day to day activities and how people managed the system and how you could find little shortcuts or long cuts. It was almost like a crash course on how to deal with the system.

Additionally, there was a common sense of emotional and psychological support with participants feeling less lonely, more comfortable opening-up to others, and reducing the isolation associated with chronic illness.

[The group was] very supportive and I wasn't really expecting that. When this ended, I was feeling kind of sad because I grew to know these people and now I won't see them

When it was the last session I was thinking "aw I'm sad this is the last session" I was just getting comfortable. Also, it has helped me outside of the group – continuing on after in my personal life. I feel like I've been more open. It helped me to open up

Multiple participants noted changes in their physical well-being and symptom burden through participation:

Sitting five minutes before the session starts, I'm sitting there not feeling good … then 45 minutes later I've written something you could consider a poem … I'm engaged and I don't feel bad anymore and I didn't take any medical intervention to make myself feel better

Missing one meeting made me realize that I do physically feel better after we get together. I don't really have any data or percentage points or anything of that nature, but it is a marked improvement in my mood and pain levels.

Three participants reported benefits specifically related to the narrative aspects of the intervention:

The two things that were most helpful was being able to talk with others going through similar ordeal to me and also being able to write and tap into my creativity in a way that my work usually allows

I really loved the approach to the group because weren't just sitting there complaining about our disease, we were actually doing something productive and thoughtful and meaningful

The writing was very healing … I loved that part, it was very, very healing. And everybody sharing was really very important to hear their stories.

Suggestions for the future

The most common suggestion from participants was to extend and expand the group – both for the exiting participants and for eligible patients in the future. Participants also reported a desire for more interpersonal connecting within the group both during the group ("*More in depth talk about individual situations and problems*") and after its conclusion ("*I would like to know how the other people in the group are doing if they were willing to put that out there. Even if it's just posting something somewhere*"). Finally, there was a desire by two participants to change the works of art used throughout the intervention that would resonate more with them or be more accessible.

Discussion

This pilot study aimed to determine the feasibility and potential benefits of a narrative medicine group for patients receiving ambulatory specialist-level palliative care. We proposed that a group therapeutic intervention rooted in narrative medicine's methodology may provide an opportunity for patients to re-encounter their lived experience by returning to them a sense of control during a time and experience that frequently lacks dignity and power (Cepeda et al. 2008; Fioretti et al. 2016). Our findings demonstrate such an intervention appears to be feasible and may be beneficial to a subset of palliative care patients. These results are in line with a growing body of evidence suggesting that engaging with and exploring one's illness experience through narrative methods may benefit patients.

While we did not see any reduction in ESAS or PDI scores, participants reported low symptom burden and high dignity prior to the intervention. However, there were reports by multiple participants that engaging in the group led to subjective reduction in their symptoms. Administering a symptom assessment tool immediately preceding and following participation in each session would have been more suitable for measuring any transient changes in symptoms associated with the intervention.

The sample in this group was diverse in terms of age, race, diagnosis, prognosis, and education. Often, support groups are organized around a common diagnosis. At least four of the participants in our study were or had been involved with disease-specific support groups. While this can undoubtedly be of use to patients, we suggest that interacting with patients with diverse diagnoses may be of value as well. One participant stated the following:

I'm in a lot of amyloidosis support groups on Facebook primarily so I get the mindset that everyone's an amyloidosis patient and I go on those sites comparing what I'm going through to others. I had to keep reminding myself that these patients are not amyloidosis patients which is, in that context, very helpful to me because I'm seeing a cross section of people dealing with things that is just much different. People who have different kinds of cancers that have different issues. More perspectives but it makes me more grateful

Challenges related to technology were only listed as a challenge and barrier to participation for one participant. However, at no point during the study did such problems appear to impede participants' ability to fully engage. Certainly, the recent increases in telehealth utilization, particularly within palliative care, likely contributed to overall patient comfort with this technology (Steindal et al. 2020). This is an encouraging finding given the potential for delivering such an intervention to a broader audience using teleconferencing software. Notably, no participant indicated the virtual delivery of the intervention as a drawback or cited challenges in fully engaging through the 6-week course. Indeed, one participant managed to participate in the weekly sessions even while visiting Europe in his final months of life.

https://doi.org/10.1017/S1478951523001499 Published online by Cambridge University Press

For patients with chronic illnesses, in particular those with life limiting disease and those receiving palliative care, there are many competing demands for time. Thus, we were unsure how participation would be prioritized by participants. Overall attendance rates ranged from 30% (1 participant) to 100% (4 participants). Additionally, post-survey responses indicated most participants found the time commitment to be manageable. One participant noted the infrequent attendance by some participants as a challenge and reported a desire for more "mandatory" attendance to facilitate closer group dynamics and build trust within the group.

These results are subject to several important limitations that warrant discussion. First, we acknowledge this was an observational study with no control group and the impact of external factors cannot be excluded. Additionally, PDI and ESAS scores at the mid-point and end of the study were assessed within one week of the preceding session though the exact timing varied by participant. Determining immediate impact of the session on mood and symptom severity by administering survey instruments immediately preceding and directly following each session would likely be more useful. Furthermore, potential biases in participant outcomes must be considered. The small sample size and the selection of participants by their treating physicians raises the risk of sampling bias. The difference between the results of the quantitative scales and the qualitative comments may have been due to a social desirability bias and confirmation bias, given that a substantial number of participants were referred directly by their palliative care physician who also conducted the sessions. It is worth noting that the research team member responsible for conducting interviews was not a member of the participants' healthcare team and all were assured that their feedback would be immediately anonymized, and would have no impact on their personal care. Lastly, this study was only available to English speaking patients restricting the generalizability of the findings to broader populations.

In summary, a narrative medicine group for ambulatory patients receiving palliative care appears to be both subjectively beneficial and feasible over a 6-week period when delivered through a virtual format. Future studies using a control group with a larger number of participants is suggested to assess the impact of a weekly narrative medicine group on symptom distress, dignity and quality of life.

Supplementary material. The supplementary material for this article can be found at https://doi.org/10.1017/S1478951523001499.

Funding. The authors report no funding sources.

Competing interests. The authors have no conflicts of interest to report relating to this study.

References

Bruera E, Kuehn N, Miller MJ, *et al.* (1991) The Edmonton Symptom Assessment System (ESAS): A simple method for the assessment of palliative care patients. *Journal of Palliative Care* **7**(2), 6–9. doi:10.1177/082585979100700202

Bruera E, Willey J, Cohen M, *et al.* (2008) Expressive writing in patients receiving palliative care: A feasibility study. *Journal of Palliative Medicine* **11**(1), 15–19. doi:10.1089/jpm.2007.0112

Cepeda MS, Chapman CR, Miranda N, *et al.* (2008) Emotional disclosure through patient narrative may improve pain and well-being: Results of a randomized controlled trial in patients with cancer pain. *Journal of Pain and Symptom Management* **35**(6), 623–631. doi:10.1016/j.jpainsymman.2007.08.011

Charon R (2001) Narrative medicine: A model for empathy, reflection, profession, and trust. *JAMA* **286**(15), 1897–1902. doi:10.1001/jama.286.15.1897

Chochinov HM, Hassard T, McClement S, *et al.* (2008) The patient dignity inventory: A novel way of measuring dignity-related distress in palliative care. *Journal of Pain and Symptom Management* **36**(6), 559–571. doi:10.1016/j.jpainsymman.2007.12.018

Division of Narrative Medicine, Columbia University (2020) https://www.mhe.cuimc.columbia.edu/division-narrative-medicine (accessed 27 November 2022).

Fioretti C, Mazzocco K, Riva S, *et al.* (2016) Research studies on patients' illness experience using the narrative medicine approach: A systematic review. *BMJ Open* **6**(7), e011220. doi:10.1136/bmjopen-2016-011220

Imrie S and Troop NA (2012) A pilot study on the effects and feasibility of compassion-focused expressive writing in Day Hospice patients. *Palliative & Supportive Care* **10**(2), 115–122. doi:10.1017/S1478951512000181

Lloyd-Williams M, Cobb M, O'Connor C, *et al.* (2013) A pilot randomised controlled trial to reduce suffering and emotional distress in patients with advanced cancer. *Journal of Affective Disorders* **148**(1), 141–145. doi:10.1016/j.jad.2012.11.013

Lloyd-Williams M, Shiels C, Ellis J, *et al.* (2018) Pilot randomised controlled trial of focused narrative intervention for moderate to severe depression in palliative care patients: DISCERN trial. *Palliative Medicine* **32**(1), 206–215. doi:10.1177/0269216317711322

Low J, Perry R and Wilkinson S (2005) A qualitative evaluation of the impact of palliative care day services: The experiences of patients, informal carers, day unit managers and volunteer staff. *Palliative Medicine* **19**(1), 65–70. doi:10.1191/0269216305pm942oa

Morris DB (2008) Narrative medicines: Challenge and resistance. *The Permanente Journal* **12**(1), 88. doi:10.7812/TPP/07-088

Petrie KJ, Fontanilla I, Thomas MG, *et al.* (2004) Effect of written emotional expression on immune function in patients with human immunodeficiency virus infection: A randomized trial. *Psychosomatic Medicine* **66**(2), 272–275. doi:10.1097/01.psy.0000116782.49850.d3

Rosenberg HJ, Rosenberg SD, Ernstoff MS, *et al.* (2002) Expressive disclosure and health outcomes in a prostate cancer population. *The International Journal of Psychiatry in Medicine* **32**(1), 37–53. doi:10.2190/AGPF-VB1G-U82E-AE8C

Smyth JM (1998) Written emotional expression: Effect sizes, outcome types, and moderating variables. *Journal of Consulting and Clinical Psychology* **66**(1), 174. doi:10.1037/0022-006X.66.1.174

Stanton AL, Danoff-Burg S, Sworowski LA, *et al.* (2002) Randomized, controlled trial of written emotional expression and benefit finding in breast cancer patients. *Journal of Clinical Oncology* **20**(20), 4160–4168. doi:10.1200/JCO.2002.08.521

Steindal SA, Nes AAG, Godskesen TE, *et al.* (2020) Patients' experiences of telehealth in palliative home care: Scoping review. *Journal of Medical Internet Research* **22**(5), e16218. doi:10.2196/16218

Taylor-Ford M (2014) Clinical considerations for working with patients with advanced cancer. *Journal of Clinical Psychology in Medical Settings* **21**(3), 201–213. doi:10.1007/s10880-014-9398-z